# **Complete Summary**

## **TITLE**

Palliative care: the practice has a complete register available of all patients in need of palliative care/support irrespective of age.

## SOURCE(S)

British Medical Association (BMA) and NHS Employers. Quality and outcomes framework guidance for GMS contract 2009/10. London (UK): British Medical Association, National Health Service Confederation; 2009 Mar. 162 p.

## **Measure Domain**

## **PRIMARY MEASURE DOMAIN**

Structure

The validity of measures depends on how they are built. By examining the key building blocks of a measure, you can assess its validity for your purpose. For more information, visit the <u>Measure Validity</u> page.

## **SECONDARY MEASURE DOMAIN**

Does not apply to this measure

# **Brief Abstract**

## **DESCRIPTION**

This measure is used to assess whether the practice has a complete register available of all patients in need of palliative care/support irrespective of age.

## **RATIONALE**

Palliative care is the active total care of patients with life-limiting disease and their families by a multi-professional team. The first National End of Life Care (EOLC) Strategy was published in July 2008. It builds on work such as the National Health Service (NHS) cancer plan 2000, National Institute for Clinical Excellence (NICE) guidance 2004, NHS EOLC programme 2005 and was informed by the consultation including primary care in the Darzi end of life workstream.

In Scotland, "Living and Dying Well, a national action plan for palliative and end of life care in Scotland" 2008 places great emphasis on the role of primary care in

providing palliative care for all patients with such needs, regardless of diagnosis. The action plan uses the concepts of planning and delivery of care, and of communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care in Scotland.

The way primary care teams provide palliative care in the last months of life has changed and developed extensively in recent years with:

- Over 99% of practices now using a palliative care register since the introduction of this indicator set.
- Specific emphasis on the inclusion of patients with non-malignant disease and of all ages since April 2008.
- Patients and carers being offered more choice regarding their priorities and preferences for care including their preferred place of care in the last days of life. (Evidence shows that more patients achieve a home death if they have expressed a wish to do so.)
- Increasing use of anticipatory prescribing to enable rapid control of symptoms if needed and a protocol or integrated care pathway for the final days of life.
- Identification of areas needing improvement by the National Audit Office, e.g., un-necessary hospital admissions during the last months of life.

The National EOLC Strategy and "Living and Dying Well" suggest that all practices should adopt a systematic approach to end of life care and work to develop measures and markers of good care. They recommend the Gold Standards Framework (GSF) and the associated After Death Analysis (ADA) as examples of good practice. Evidence suggests that over 60% of practices across the UK now use GSF to some degree to improve provision of palliative care by their primary care team.

The introduction of Gold Standard Framework (GSF) to primary care and its associated audit tool, the ADA are associated with a considerable degree of research and evaluation. GSF provides ideas and tools that help practices to focus on implementing high quality patient centred care.

About 1% of the population in the UK die each year (over half a million), an average of 20 deaths per GP per year. A quarter of all deaths are due to cancer, a third from organ failure, a third from frailty or dementia, and only one twelfth of patients have a sudden death. It should be possible therefore to predict the majority of deaths, however, this is difficult, with errors occurring, 30 per cent of the time. Two thirds of errors are based on over optimism and one third on over pessimism. However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need.

Identifying patients in need of palliative care, assessing their needs and preferences and proactively planning their care, are the key steps in the provision of high quality care at the end of life in general practice. Therefore this Quality and Outcomes Framework (QOF) indicator set is focused on the maintenance of a register, (identifying the patients) and on regular multidisciplinary meetings where the team can ensure that all aspects of a patient's care have been assessed and future care can be co-ordinated and planned proactively.

The register applies to all patients fulfilling the criteria regardless of age or diagnosis. The creation of a register will not in itself improve care but it enables the wider practice team to provide more appropriate and patient focussed care.

This measure is one of two Palliative Care measures.

## PRIMARY CLINICAL COMPONENT

Palliative care/support; patient registry

#### **DENOMINATOR DESCRIPTION**

This measure applies to practices whose patient population includes individuals who are in need of palliative care/support (one practice at a time).

#### **NUMERATOR DESCRIPTION**

The practice has a complete register available of all patients in need of palliative care/support irrespective of age (see the related "Numerator Inclusions/Exclusions" field in the Complete Summary)

## **Evidence Supporting the Measure**

# **EVIDENCE SUPPORTING THE CRITERION OF QUALITY**

- A clinical practice guideline or other peer-reviewed synthesis of the clinical evidence
- A formal consensus procedure involving experts in relevant clinical, methodological, and organizational sciences

# **Evidence Supporting Need for the Measure**

#### **NEED FOR THE MEASURE**

Unspecified

# **State of Use of the Measure**

#### **STATE OF USE**

Current routine use

## **CURRENT USE**

Internal quality improvement National reporting Pay-for-performance

# **Application of Measure in its Current Use**

## **CARE SETTING**

Physician Group Practices/Clinics

#### PROFESSIONALS RESPONSIBLE FOR HEALTH CARE

Physicians

## LOWEST LEVEL OF HEALTH CARE DELIVERY ADDRESSED

**Group Clinical Practices** 

## **TARGET POPULATION AGE**

Does not apply to this measure

## **TARGET POPULATION GENDER**

Does not apply to this measure

## STRATIFICATION BY VULNERABLE POPULATIONS

Does not apply to this measure

# **Characteristics of the Primary Clinical Component**

# INCIDENCE/PREVALENCE

See the "Rationale" field.

# **ASSOCIATION WITH VULNERABLE POPULATIONS**

See the "Rationale" field.

## **BURDEN OF ILLNESS**

Unspecified

# **UTILIZATION**

Unspecified

## **COSTS**

Unspecified

# **Institute of Medicine National Healthcare Quality Report Categories**

## **IOM CARE NEED**

Not within an IOM Care Need

#### **IOM DOMAIN**

Not within an IOM Domain

## **Data Collection for the Measure**

#### **CASE FINDING**

Does not apply to this measure

## **DENOMINATOR SAMPLING FRAME**

Does not apply to this measure

## **DENOMINATOR INCLUSIONS/EXCLUSIONS**

## **Inclusions**

This measure applies to practices whose patient population includes individuals who are in need of palliative care/support (one practice at a time).

## **Exclusions**

Unspecified

#### RELATIONSHIP OF DENOMINATOR TO NUMERATOR

Does not apply to this measure

## **DENOMINATOR (INDEX) EVENT**

Does not apply to this measure

## **DENOMINATOR TIME WINDOW**

Does not apply to this measure

# **NUMERATOR INCLUSIONS/EXCLUSIONS**

## **Inclusions**

The practice has a complete register available of all patients in need of palliative care/support irrespective of age

A patient should be included on the register if any of the following apply:

- 1. Their death in the next 12 months can be reasonably predicted
- 2. They have advanced or irreversible disease and clinical indicators of progressive deterioration and thereby a need for palliative care e.g., they have 1 core and 1 disease specific indicator in accordance with the Gold Standards Framework (GSF) Prognostic Indicators Guidance
- 3. They are entitled to a DS 1500 form. (The DS 1500 form is designed to speed up the payment of financial benefits and can be issued when a patient is considered to be approaching the terminal stage of their illness. For these purposes, a patient is considered as terminally ill if they are suffering from a progressive disease and are not expected to live longer than six months.)

The register applies to all patients fulfilling the criteria regardless of age or diagnosis.

## **Exclusions**

Unspecified

# MEASURE RESULTS UNDER CONTROL OF HEALTH CARE PROFESSIONALS, ORGANIZATIONS AND/OR POLICYMAKERS

The measure results are somewhat or substantially under the control of the health care professionals, organizations and/or policymakers to whom the measure applies.

## NUMERATOR TIME WINDOW

Encounter or point in time

## **DATA SOURCE**

Registry data

# LEVEL OF DETERMINATION OF QUALITY

Does not apply to this measure

## PRE-EXISTING INSTRUMENT USED

Unspecified

# **Computation of the Measure**

## **SCORING**

Categorical Variable

## **INTERPRETATION OF SCORE**

Passing score defines better quality

## **ALLOWANCE FOR PATIENT FACTORS**

Does not apply to this measure

## STANDARD OF COMPARISON

External comparison at a point in time Internal time comparison

## **Evaluation of Measure Properties**

#### **EXTENT OF MEASURE TESTING**

Unspecified

# **Identifying Information**

#### **ORIGINAL TITLE**

PC 3. The practice has a complete register available of all patients in need of palliative care/support irrespective of age.

#### **MEASURE COLLECTION**

Quality and Outcomes Framework Indicators

## **MEASURE SET NAME**

Palliative Care

## **DEVELOPER**

British Medical Association National Health Service (NHS) Confederation

## **FUNDING SOURCE(S)**

The expert panel who developed the indicators were funded by the English Department of Health.

## COMPOSITION OF THE GROUP THAT DEVELOPED THE MEASURE

The main indicator development group is based in the National Primary Care Research and Development Centre in the University of Manchester. They are: Professor Helen Lester, NPCRDC, MB, BCH, MD; Dr. Stephen Campbell, NPCRDC, PhD; Dr. Umesh Chauhan, NPCRDC, MB, BS, PhD.

Others involved in the development of individual indicators are: Professor Richard Hobbs, Dr. Richard McManus, Professor Jonathan Mant, Dr. Graham Martin, Professor Richard Baker, Dr. Keri Thomas, Professor Tony Kendrick, Professor Brendan Delaney, Professor Simon De Lusignan, Dr. Jonathan Graffy, Dr. Henry Smithson, Professor Sue Wilson, Professor Claire Goodman, Dr. Terry O'Neill, Dr. Philippa Matthews, Dr. Simon Griffin, Professor Eileen Kaner.

## FINANCIAL DISCLOSURES/OTHER POTENTIAL CONFLICTS OF INTEREST

None for the main indicator development group.

#### **ENDORSER**

National Health Service (NHS)

## **ADAPTATION**

Measure was not adapted from another source.

#### **RELEASE DATE**

2006 Feb

#### **REVISION DATE**

2009 Mar

#### **MEASURE STATUS**

This is the current release of the measure.

This measure updates a previous version: British Medical Association (BMA), and NHS Employers. Quality and outcomes framework guidance for GMS contract 2008/09. London (UK): British Medical Association, National Health Service Confederation; 2008 Apr. 148 p.

## SOURCE(S)

British Medical Association (BMA) and NHS Employers. Quality and outcomes framework guidance for GMS contract 2009/10. London (UK): British Medical Association, National Health Service Confederation; 2009 Mar. 162 p.

## **MEASURE AVAILABILITY**

The individual measure, "PC 3. The Practice Has a Complete Register Available of All Patients in Need of Palliative Care/Support Irrespective of Age," is published in the "Quality and Outcomes Framework Guidance." This document is available from the British Medical Association Web site.

## **NQMC STATUS**

This NQMC summary was completed by ECRI on May 22, 2006. The information was verified by the measure developer on August 11, 2006. This NQMC summary was updated by ECRI Institute on January 16, 2009. This NQMC summary was updated again by ECRI Institute on October 1, 2009. The information was verified by the measure developer on March 4, 2010.

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